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ABSTRACT

This document details the strategic plan of the National Institute of Child Health and Human Development to address disparities in health and developmental outcomes among Americans, particularly between and among racial and ethnic groups. Following a description of the plan's development, scientific areas of interest, and important themes, the document presents the plan's target areas. Each area description includes a discussion of facts, current research, and future goals and objectives. The areas are: (1) infant and maternal mortality and morbidity; (2) reproductive health; (3) HIV/AIDS (targeting women and teens); (4) early antecedents of disparities in disease and growth (fetal mechanisms, obesity and nutrition); (5) early antecedents of child well-being and adverse behaviors; (6) school readiness and cognitive and behavioral development; (7) restoring function and preventing disability (physical and developmental); (8) training and career development; and (9) outreach to communities and their institutions. A roster of advisors is appended. (EV)

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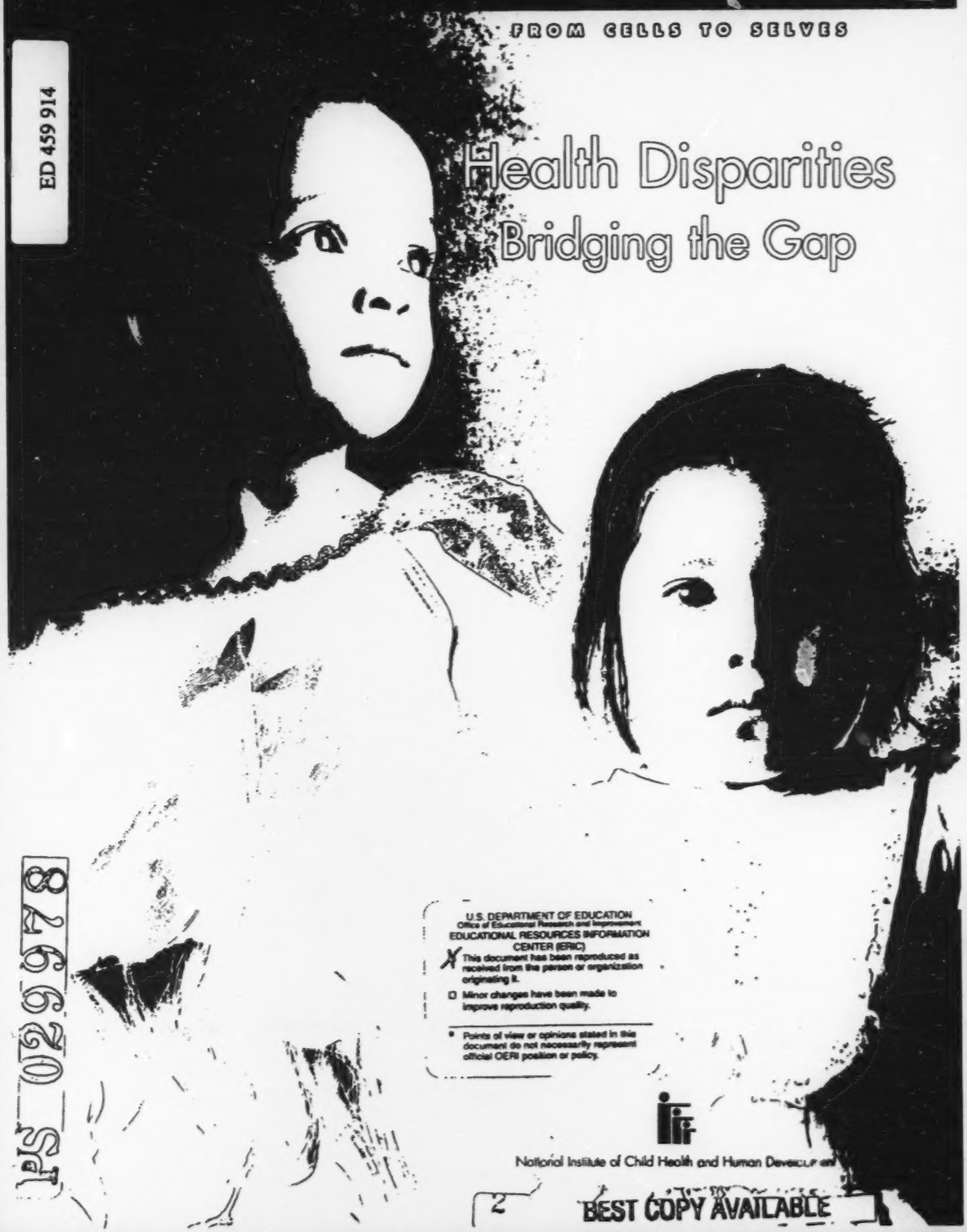
FROM CELLS TO SELVES

Health Disparities
Bridging the Gap



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Health Disparities
Bridging the Gap

National Institute of Child Health and Human Development

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The NICHD Mission

Since its inception in 1962, the National Institute of Child Health and Human Development (NICHD) has dedicated its research to understanding the dynamic biological, behavioral, and social processes that dictate physical, emotional, and cognitive growth. NICHD research starts early, from before conception through the transitions of infancy, childhood, and adolescence, which set the foundation for conditions, diseases, and behaviors that last a lifetime. The Institute creates the knowledge to understand the complex interplay of processes that transform cells into healthy functioning individuals, free of disease and disabilities. When this goal is not achieved, or achieved unequally by different groups, the NICHD mission is to understand why, and to develop remedies to ensure the healthy functioning of all infants, children, youth, and families.

The NICHD mandate also includes addressing: 1) the biological, physical, social, individual, and community forces affecting population dynamics and human reproduction—many of these forces contribute to the earliest beginnings of health disparities; and 2) the science to help persons with physical disabilities restore, replace, enhance, and prevent decline in function.

NICHD—Building Scientific Bridges to Health

Building Bridges . . .

Building bridges to bring communities together takes conscious, dedicated, and collaborative effort. It requires a great understanding of the natural and manmade forces that interact over time. Construction must be thoughtfully and carefully designed, with foundations rooted in science, but firmly grounded in the communities to be served.

In some ways, bridging, and more importantly eliminating, the gap in health disparities takes the same dedicated effort. Health disparities do not "just occur"; they develop over time as natural biological and behavioral forces interact with such factors as poverty and discrimination, and are modified by a variety of community, social, and economic forces. Closing the health disparity gap demands an indepth understanding of these processes and mechanisms as they interact over lifespans. Finally, it requires the conscientious design of interventions, rooted in science, but implemented through acts of individuals and communities working together.

. . . That Span Generations

Scientists believe that the best time to eliminate disparities may start well before birth and extend through the first decade of life. Although genetics and related biological factors may provide initial blueprints, numerous events and experiences from conception onward—be they biological, developmental, or social—interact with this "programming." How and when these factors interact may determine whether or not individuals start life on a healthy and fully functional path. No matter which path is taken, however, the cumulative effects of these events can last a lifetime or, as scientists now believe, can be passed down to future generations.

Building on this premise, scientists, including many supported by the National Institute of Child Health and Human Development (NICHD), are poised to conduct basic and applied research that can help to eliminate health disparities. This is particularly true for eliminating some of our Nation's most persistent health disparities, starting with infant and maternal mortality. As noted, the Institute's mission combines a unique developmental perspective with critical partnerships to further the science underlying health disparities.

The NICHD Health Disparities Plan

Building by Design

To build the NICHD strategic plan concerning health disparities, the Institute drew from its existing, distinguished, and strong research portfolio aimed at eliminating health disparities. Reflecting the Institute's mission, the unifying concept of the plan is development, starting before conception and continuing throughout the lifespan and across generations. The Institute's long experience investigating the complex biological and environmental interactions that drive developmental processes is invaluable when clarifying the causes of racial and ethnic, and even community-based, disparities. By focusing and coordinating research on gestation and the early years of life, including the transitions into and out of adolescence and young adulthood, the NICHD can address not only the development, but the critical timing of preventive and therapeutic strategies.

To build the strategic plan organizationally, the NICHD drew upon a vast array of professional and public input. Within the Institute, a working group that included more than 30 scientific, planning, and policy staff drew upon ongoing planning efforts; recent forums, workshops, conferences, and research findings; as well as discussions with researchers across the country to suggest initial goals and objectives. These were consolidated into a draft plan that was shared with executive staff within the NICHD and the National Institutes of Health (NIH).

In addition, the draft plan was posted on the NICHD Web site to encourage broad public comment; it was also shared with our Council members and the Friends of the NICHD. At the same time, the Director of the NICHD sought input and guidance from a panel of 10 national experts (see Appendix), representing a broad array of scientific and policy disciplines, as well as individuals who are authorities on, and have personal experience working with, health disparity issues.

Panel members not only reviewed the content of the plan but suggested priorities among the many goals and initiatives, noting that the plan builds on the Institute's strengths. This includes targeting research to the two most vulnerable stages of human development: 1) very early development, with a focus on perinatal outcomes and infant mortality, and 2) the transition from adolescence to adulthood, a period where youth may miss important developmental milestones due to a complicated mix of biological, behavioral, and social factors. The members also endorsed the blending of scientific approaches, ranging from those used in biology and clinical medicine to those used in the behavioral and social sciences.

After all comments were consolidated and reviewed, the plan was revised and finalized. Although in printed format, this plan is a flexible blueprint that will guide new and ongoing activities, and one that will be continuously reviewed in light of scientific findings, advances, and resources.

Scientific Areas of Interest

For purposes of this strategic plan, the NICHD defines "health disparities" as including significant differences in health and developmental outcomes, particularly between and among racial and ethnic groups.

For the NICHD, emphasis is placed on differences in health and developmental outcomes whose origins may start before pregnancy and extend into early adulthood, or that result directly from a range of physical disabilities, no matter when they occurred. Our goal is to understand the mechanisms by which these racial and ethnic differences occur in light of the complex interactions between basic biological processes and such factors as poverty, education, and "community" with its distinct geographic, environmental, and cultural realities.

These differences can be both positive and negative. While much of the plan targets reducing or eliminating many of the negative differences, the NICHD recognizes the importance of understanding how and why some minority and ethnic populations have better health outcomes than others, especially given the many adverse situations in which they may live. This "paradox" is particularly apparent in some immigrant communities where, for example, data have shown that recent immigrant women may have better pregnancy outcomes on average than women who are the first generation of their families to be born in the United States. By understanding the mechanisms that contribute to this paradox, scientists can identify "protective" factors, both biological and otherwise, that lead to resiliency and provide the foundation for successfully bridging the gaps.

As evident from the descriptions below, the scientific areas that form the plan's framework are not only key to our mission, but represent significant disparities requiring immediate attention:

A— INFANT AND MATERNAL MORTALITY AND MORBIDITY is a critical research area for the Institute. Eliminating health disparities in infant/maternal health is also a prime objective of our Nation's public health policy.

B— REPRODUCTIVE HEALTH, another area that is key to our mission, addresses biological and behavioral mechanisms that compromise the reproductive well-being of men and women, including many minority groups. It also includes issues affecting family planning and sexually transmitted disease, which are covered in Healthy People 2010, the update of the Nation's health objectives developed by the U.S. Department of Health and Human Services (DHHS).

C— HIV/AIDS—TARGETING WOMEN AND TEENS is a key NICHD research area from both a biological and behavioral perspective. Related to issues of reproductive health, this plan addresses the high impact of these conditions on women and youth of color in the United States.

D— EARLY ANTECEDENTS OF DISPARITIES IN DISEASE AND GROWTH addresses the most important roots of health disparities (e.g., diabetes, heart disease, obesity) that start with prenatal and gestational mechanisms. It also addresses how early nutrition contributes to these differences.

E— EARLY ANTECEDENTS OF CHILD WELL-BEING AND ADVERSE BEHAVIORS addresses how the development and well-being of children are affected by poverty, and other family and community factors, which in turn contribute to poor health outcomes and the disproportionate incidence of injuries and violence in many minority communities.

F— SCHOOL READINESS, COGNITIVE AND BEHAVIORAL DEVELOPMENT addresses differences in acquiring basic cognitive and learning skills that keep minority youth from breaking the disparity cycle. Research in this area has attracted significant public interest and support.

G— RESTORING FUNCTION AND PREVENTING DISABILITY is a unique, yet overlooked area that recognizes the special needs of minority families in overcoming the burden of physical or developmental disabilities.

H— TRAINING AND CAREER DEVELOPMENT in all areas of research, particularly for minority researchers, scientists, and clinicians, will provide the critical human resources needed to improve the health of minority communities.

I— OUTREACH TO COMMUNITIES AND THEIR INSTITUTIONS involves translating scientific findings concerning health disparities into a common language that enables communities to act upon them. It also implies participating, giving back to communities, and encouraging partnerships so that the Nation gets the best return on its research investments.

Important Themes

Although the following themes and issues may not be stated explicitly or repeated throughout the plan, the NICHD recognizes their importance when conducting research concerning health disparities.

- A range of different types of research must be supported to address health disparities. This includes basic biomedical and behavioral studies to identify the primary mechanisms contributing to a particular health disparity, as well as any related clinical, intervention, and effectiveness studies. The Institute must also balance support of one-time-only projects with the need to support new, extensive, ongoing longitudinal studies that may help to explain the development of health disparities over time. Likewise, the NICHD must build upon successful existing research networks or projects in addition to developing initiatives that require investment in new research infrastructure.

- The newest scientific breakthroughs, advances, and technologies, such as those stemming from genomics and from the newest imaging technologies, should be incorporated when appropriate and feasible in the design of health disparities research.

- The heterogeneity of racial, ethnic, and other population groups characterized by poor health outcomes must be recognized and considered in designing research. Often these differences are linked to variations associated with cultural differences within a community, neighborhood, or geographic region. The most accurate indicators of successful interventions are likely to be those that can account for these differences. Often the disparities may reveal themselves in differences associated with various communities and their institutions, such as those found in a wide range of Native American and immigrant communities. The differences also may be found when comparing populations isolated by geography and resources. Similarly, family-based research and studies that span generations are useful in understanding health disparities, especially when examining the behavioral as well as genetic aspects of adverse health outcomes.

- To be successful, support for health disparities research requires multidisciplinary and collaborative initiatives and partnerships, not only between other NIH institutes and offices that share our interests, but with other Federal agencies (e.g., Centers for Disease Control and Prevention, Health Resources and Services Administration, Agency for Healthcare Research and Quality, Indian Health Service, Department of Justice, Department of Education), nonprofit organizations, and advocacy groups.

- In addition to the human and financial resources required to implement the plan successfully, the NICHD must set priorities guided by our unique strengths.

The NICHD's Unique Perspectives in Health Disparities

A INFANT AND MATERNAL MORTALITY AND MORBIDITY

The Facts

- Infant mortality and related rates:
  - Despite a 16% overall decline in infant mortality over the last decade, the rate among African Americans remains more than twice that of Whites.
  - African American infants are more than twice as likely to be born low birth weight (LBW) and more than three times as likely to be born very low birth weight (VLBW) as White neonates. As a result, prematurity and LBW are the leading causes of death among African American infants, occurring at five times the rate of Whites.
  - By comparison, the overall rate of low birth weight for Hispanics, who have a slightly higher rate of poverty than African Americans, is about the same as it is for Whites. Overall, infants born to Asian mothers have the lowest infant mortality rates of any ethnic or racial group in the United States.
  - These overall rates vary broadly within racial and ethnic groups: Mothers of Puerto Rican origin were 57% more likely to have LBW infants than Mexican mothers; likewise, Filipino mothers were 67% more likely to have a LBW infant than Chinese mothers.

- Causes of disparities/prematurity:
  - Researchers suggest that one-third of premature births could be due to infection/inflammation.
  - The prevalence of certain infections varies by race, e.g., the incidence of bacterial vaginosis is 2.5 times higher among African American women than among White women.
  - Infection resulting in preterm delivery is much more common at earlier gestational ages.
  - While the poverty rate in African Americans is more than twice the rate of Whites, studies show that differences in infant mortality and morbidity rates cannot be explained by inequalities in social or economic circumstances alone.

- Maternal mortality/morbidity in the United States:
  - Although maternal mortality rates have decreased dramatically, maternal death is four times higher among African American women than among White women, and is often preventable.
  - Ectopic pregnancy and preeclampsia are the number one and number two leading causes of maternal mortality and the leading causes of maternal mortality in African American women.
  - The risk for pregnancy-related mortality is 1.6 times higher for women of other races than for White women.

- The NICHD supports an extensive portfolio of basic, clinical, and behavioral research targeting prenatal, perinatal, and postnatal events and processes that ultimately influence pregnancy and maternal health outcomes among minorities.

- The NICHD supports the Maternal-Fetal Medicine Unit and the Neonatal Research Networks, with the ultimate goal of reducing disparities in infant/maternal mortality rates. Many of the sites are located in inner cities serving predominately African American and Hispanic populations.

Current Research

- Much of the Institute's current research in this area targets racial and ethnic minority populations, and addresses issues that can help to reduce these health disparities.

Examples of many targeted efforts include:

- Studies on antibiotic treatment for bacterial vaginosis in African American women.
- The "Initiative to Reduce Infant Mortality in Minority Populations in the District of Columbia" (or, the "D.C. Initiative"), which is co-funded with the Office of Research on Minority Health and targets interventions to the District's minority population.
- The Sudden Infant Death Syndrome (SIDS) "Back to Sleep" campaign and activities with partner organizations from the African American community and other racial and ethnic groups. The goal is to develop culturally sensitive campaigns that can help to eliminate the disparity in the prevalence of back-sleeping for African American infants within 3 years of the new outreach program.
- Studies that analyze the disparity in medical, behavioral, and external SIDS risk factors for African Americans and Native Americans.
- "The Puerto Rico Maternal and Infant Health Project," which examines factors leading to health disparities in the Puerto Rican community, and projects targeting the Mexican American population to discern factors leading to favorable pregnancy outcomes.
- The Maternal Lifestyles Study (MLS), which is examining the developmental outcomes of infants exposed to drugs *in utero* and conducting important comparative analyses by racial/ethnic group.
- Various studies concerning maternal mortality that examine such topics as the impact of diabetes, hypertension, stress, nutrition, and partner violence on pregnancy outcomes; many of these studies target minority women.

Future Goals/Objectives

Goal 1: Build upon the NICHD's extensive intramural and extramural research portfolio to answer critical questions on health disparities in infant and maternal health.

- Develop a program to supplement grants most likely to yield immediate answers to critical biological and behavioral questions targeting differences in infant and maternal mortality and major morbidities. This will help to increase the representation of diverse

racial and ethnic groups in ongoing studies, and findings can be used to develop further targeted research. This effort will include methodological seminars and workshops.

Goal 2: Better understand the etiology, pathophysiology, and related social and behavioral factors, specifically leading to preterm births and low birth weight.

- Significantly expand the scope of current efforts in the NICHD's intramural Perinatal Research Branch (PRB). This would allow the PRB to relocate to an area and institution that serves significantly large numbers of high-risk and minority patients, expand opportunities for minority clinical fellowships, and more quickly translate findings into immediate use.

- Clarify the biologic and social etiologies of health disparity in preterm births and in adverse neonatal outcomes associated with infectious/inflammatory disease processes, through multidisciplinary, collaborative research, and by augmenting current Network protocols. Target biologic factors associated with the disease process that might be specific to African American women.

- Develop and implement clinical trials to prevent preterm births and adverse neonatal outcomes associated with infectious/inflammatory disease processes in minority women. Test different treatment regimens, as well as preventive and counseling strategies.

- Identify genetic factors that may predispose women and their infants to preterm birth and low birth weight, targeting racial/ethnic populations. Some areas of interest would include genetic markers or genetic differences that may influence implantation and fetal growth.

- Expand the D.C. Initiative with new interventions, targeting African American and Hispanic teens that simultaneously address psychosocial and behavioral risk factors to prevent preterm births and low birth weight.

- Increase research training opportunities concerning health disparities in the perinatal period through the Specialized Clinical Investigator Development Award, which is a mentored research program operating in the NICHD clinical networks.

Goal 3: Eliminate the disparate prevalence of risk factors in the sleep environment that ultimately influence the significant disparity in SIDS rates between racial and ethnic groups.

- Expand the intensive community-based outreach campaign with minority populations to reduce risks in the infant sleep environment. These risks include sleeping on the stomach, sleeping on soft mattresses or sofas, and using quilts and pillows. Continue related evaluation activities.

Goal 4: Create unique research infrastructures to help eliminate the racial/ethnic disparities in the causes of postneonatal mortality/morbidity rates, and conditions of infancy and early childhood associated with less than optimal birth outcomes.

- Create a research infrastructure, linked to community-based institutions, addressing the unique health needs of minority communities, that will 1) conduct basic research and design multidisciplinary interventions addressing poor outcomes from late pregnancy through early childhood, 2) provide opportunities for community-based research training, and 3) provide research-based information to the community. The research would simultaneously emphasize how

community, family, and socioeconomic status shape the biological processes that govern health and development.

- Collaborate with the National Institute on Alcohol Abuse and Alcoholism to examine factors leading to the pathogenesis of poor fetal and infant outcomes among American Indians and Alaskan Natives. Assess high prevalence of drinking during pregnancy, fetal alcohol syndrome, related pathologies, and possible association with SIDS.

Goal 5: Target research efforts to reduce the significant disparity in adverse maternal events, including maternal mortality between racial and ethnic groups.

- Target research to better understand the basic physiologic mechanisms leading to ectopic pregnancy and preeclampsia. Use this knowledge, combined with social/cultural data, to design targeted interventions to improve pregnancy outcomes for minority women.
- Support collaborative research to create a national database of maternal deaths that would capture information from medical histories, autopsies, and forensic investigations of deaths among women of childbearing age. Based on analyses, develop appropriate medical care protocols and plans for prevention strategies.

Goal 6: Collaborate with other agencies in their efforts to identify critical differences in quality of perinatal, maternal, and infant care that may lead to disparities in maternal and infant health outcomes. Identify factors and design immediate actions.

- Support collaborative research symposia, program assessments/reviews, and other efforts to identify quality-of-care factors and develop interventions or remedial actions. Work with the Agency for Healthcare Research and Quality, other DHHS agencies, and community and professional groups.

B REPRODUCTIVE HEALTH

The Facts

- The permanent consequences of reproductive choices and disease burden fall disproportionately on women, particularly in the African American community, where many households formed by these choices are headed by women and live in poverty.

- Women who are poor (under 100% of the Federal poverty level) have an unintended pregnancy rate that is twice the national average.

- Puberty occurs approximately one year earlier in African American females compared with White females. Therefore, the reproductive health needs and associated emotional, social, and cultural effects of puberty may require earlier monitoring, treatment, and/or intervention than previously thought.

- Although unintended pregnancy rates have declined overall, the unintended pregnancy rates remain high for some minorities: Nearly 1 in 10 African American women and 1 in 14 Hispanic women of reproductive age experience an unintended pregnancy each year.

- 12 to 18 million or 20 to 30% of all women of reproductive age have leiomyomata uteri, or uterine fibroids. African American women are diagnosed with fibroids up to two to three times more frequently than White women. Uterine fibroids, which can severely limit a woman's reproductive options, remain the number one reason for hysterectomy.

- The overall disparity in sexually transmitted disease (STD) rates is enormous. For example:
  - In 1998, the rate of gonorrhea remained 30 times greater for African Americans than for Whites, and 3 times greater for Hispanics. While part of this disparity is due to the fact that African Americans are more likely to seek care in public clinics, which generally report STDs better than private providers, other important factors contribute to this disparity, including poverty, social networks, and health-seeking behaviors.
  - The adolescent gonorrhea rate is 4.6 times that of the total population, and the adolescent chlamydia rate is 6 times that of the total population.
  - The 1998 gonorrhea rate among African American adolescents ages 15 to 19 was 23 times higher than it was for White adolescents in the same age range. Among 20- to 24-year-olds, the gonorrhea rate among African Americans was almost 27 times greater than among Whites.
  - In 1998, the rate of congenital syphilis was 30 times higher among African American infants and nine times higher among Hispanic infants than among White infants. Although completely preventable, congenital syphilis can cause serious physical deformities and mental retardation.

Current Research

- The NICHD supports basic, clinical, behavioral, and demographic studies concerning the mechanisms, treatments, outcomes, and behaviors that allow individuals to safely and effectively regulate their fertility, alleviate infertility, prevent STDs, and overcome a range of diseases/disorders of the reproductive system.

- Many ongoing studies emphasize health disparity issues. For example, researchers are studying:
  - Comparative risk of hormone replacement therapy for uterine fibroids in both African American and White women.
  - Risk factors to help predict ectopic pregnancy more definitively and quickly. This is key to eliminating this leading cause of maternal death among African American women.
  - Cultural, psychological, and other predictors of unintended pregnancy in racially and ethnically diverse, and low-income groups.
  - The social context of teen's health-promoting and risk behaviors, and interventions to help prevent unwanted pregnancies—especially among minority teens.

Future Goals/Objectives

Goal 1: Reduce disparities in unwanted pregnancy by understanding and better addressing the barriers to appropriate contraceptive services.

- Support a special program effort, "Improving Contraceptive Services to Minority Women," to better understand the barriers that exist in minority populations, to encourage effective use of contraception and to design culturally, socially, and age-appropriate interventions. Efforts will include basic studies to identify specific sources of risk and tailor strategies to meet these needs.

- Support a new phase of the D.C. Initiative, specifically the protocol to develop an intervention program to delay sexual activity, and extend the program to children in the preadolescent years, their parents, and young males.

- Support research on the factors leading to infertility among minority men and women and the reasons for lower use of infertility services in minority populations, leading to improved strategies for infertility prevention and treatment.

Goal 2: Support major research efforts to address the causes of excess reproductive morbidity among African American women.

- Expand basic science and translational research studies of uterine fibroids to understand the biological reasons for increased incidence in African American women, and to determine whether there is a familial predisposition to this condition.

- Develop a cooperative clinical treatment network to improve the diagnosis and management of uterine fibroids, including ways to reduce surgical interventions. Encourage involvement of community-based practitioners to aid in recruitment and to ensure diversity in the teams conducting such research.

- Expand current Women's Contraceptive and Reproductive Experiences (CARE) Study to allow researchers to analyze racial/genetic differences in breast cancer risk and oral contraceptive use.

Goal 3: Improve prevention, screening, and treatment of STDs, addressing the needs of different racial and ethnic populations, and to reduce disparities in reproductive health and in pregnancy outcomes.

- Expand investigator-initiated research on behaviors related to the prevention and treatment of STDs, emphasizing sociocultural perspectives and beliefs concerning STDs and related barriers to prevention as a critical step in designing interventions.

- Support multidisciplinary collaborative research on barriers that prevent minority women from being appropriately diagnosed and treated for STDs such as syphilis, and then passing the disease on to infants. Design effective interventions to help reduce preventable cases of congenital syphilis.

Goal 4: Strengthen reproductive research infrastructure at minority institutions.

- Develop an enhanced research infrastructure in the reproductive sciences that will address the needs of minority researchers through the Specialized Reproductive Science Research Centers at Minority Institutions Program. This will encourage collaborations between scientists at minority institutions and other NICHD-funded programs.

© HIV/AIDS—TARGETING WOMEN AND TEENS

The Facts

- Despite stabilization of overall incidence rates in the United States, HIV transmission and the incidence of new AIDS cases have increased for such subpopulations as women and youth, particularly those of color.
  - Worldwide, 90% of new infections are through heterosexual transmission, placing women at increased risk of infection; most of these new infections occur in minority women.
  - In the United States, by the end of 1998, 57% of women with AIDS were African American and 20% were Hispanic. Of women newly diagnosed with HIV, 81% were African American or Hispanic. Emerging data suggest that some aspects of HIV disease in women differ markedly from those in men.
  - HIV infection rates continue to rise for American youth. In addition, in 1998, the majority of reported AIDS cases for youth between ages 13 and 19 are among youth of color—57% African American and 23% Hispanic.
  - A similar percentage distribution characterizes young adults ages 20 to 24, many of whom likely acquired their infections as teens. In addition, the expanding HIV/AIDS epidemic among teens is increasingly female and sexually transmitted.

Current Research

- Over the decade, the NICHD has fostered a range of clinical, applied, translational, and behavioral research to:
  - Define the epidemiology and natural history of HIV infection in women, infants, children, and adolescents (e.g., support of the Women and Infants Transmission Study).
  - Provide national clinical networks to rapidly advance prevention and treatment in trials primarily serving minority patients, including the 1) Pediatric and Maternal HIV Clinical Trials Network and 2) Adolescent Medicine HIV/AIDS Research Network (AMHARN).
  - Develop microbicides/spermicides to allow women, particularly in vulnerable or high-risk relationships, to protect themselves from unwanted pregnancy and HIV infection.
  - Design and evaluate effective behavioral interventions, particularly targeting minority populations, many in inner-city areas.

- Examples of some targeted studies include:
  - Studies assessing the transferability of successful interventions targeting minority youth in one location (e.g., African American youth on the Eastern Seaboard) to those in another (e.g., Hispanic youth in Texas).
  - The design and evaluation of interventions to improve minority women's and couples' skills at negotiating behaviors that can prevent both unwanted pregnancy and HIV infection, and to increase their consistent and correct use of protective behaviors.

Future Goals/Objectives

Goal 1: Expand and intensify HIV prevention efforts, targeting sexual transmission and related high-risk behaviors, in racial/ethnic minority populations.

- Design, implement, and evaluate interventions based on the science of social/sexual networks to help prevent the sexual transmission of HIV, especially in high-risk communities, including minorities and teens.

- Support research to link social and cultural understandings of gender, gender-related beliefs and expectations, and gender dynamics, to account for how these factors may influence HIV risk among different racial, ethnic, and socioeconomic groups.

- Support research to better understand the impact of demographic and social trends (i.e., changes in family structure, marriage, and labor rates) on sexual behaviors related to HIV risk in different racial and ethnic populations.

- Support research to better understand the influence of interpersonal and peer-related factors on HIV risk in different racial and ethnic populations.

- Strengthen partnerships with institutions based in racial and ethnic communities, to develop more effective, research-based, HIV intervention programs (particularly targeting high-risk sexual behavior) that are closely linked to community needs, while generating new scientific data.

- Support research to understand how the media differentially targets, represents, and exposes minority populations to messages involving high-risk behaviors that can place these populations at risk for HIV infection.

Goal 2: Lead scientific efforts to better understand the pathogenesis of HIV infection among minority women, and tailor protocols, treatments, and regimens to their needs.

- Develop and support the Women's HIV Pathogenesis Program to better understand the causal relationships between HIV pathogenesis and factors unique to women (such as their reproductive physiology), directing studies to answer questions in minority populations. Investigate ways to improve the recruitment and retention of minority women in these studies and assess how their participation may influence behavior change.

Goal 3: Lead research to develop more effective means of preventing and treating HIV in minority youth, using multidisciplinary and developmentally appropriate methodologies and resources.

- Initiate an Adolescent Trials Network (ATN) to develop collaborative, primary prevention studies, as well as studies of effective and appropriate antiretroviral therapy in adolescent, high-risk, primarily minority populations. This would include support of Project ACCESS (Adolescents Connected to Care, Evaluation, and Special Services), a social marketing program to encourage teens to access health care and, if appropriate, enrollment in clinical studies.

D EARLY ANTECEDENTS OF DISPARITIES IN DISEASE AND GROWTH

Part 1: Understanding the Fetal Mechanisms Leading to Health Disparities

The Facts

- Scientists believe that inequalities in health start with the earliest prenatal and gestational mechanisms. Not all of these events are under genetic control.
  - The early interactions between fetal, maternal, and external factors may explain much of the health disparities seen in adult rates of hypertension, obesity, diabetes mellitus, and coronary artery disease.
  - These interactions may lead to fetal "programming" contributing to changes that may be transmitted across generations, and perpetuating disparities.
- Fetal conditions such as small-for-gestational-age and intrauterine growth retardation are important biomarkers since these conditions are associated with increased risk of diabetes, obesity, coronary artery disease, and hypertension, which occur disproportionately in African American populations.
  - Birth weight is the most reliable index of fetal growth. Depending on their age, African American mothers are up to two-thirds more likely to have a previous preterm or small-for-gestational-age infant.

Current Research

- The NICHD supports basic and clinical research to understand "fetal programming" and many factors that perturb fetal development *in utero* through research on pregnancy and perinatology, developmental biology, and related studies.
  - Many studies in this area target low-income or minority women, and include research on maternal behaviors (smoking/drug use) that influence the intrauterine environment; the impact of diabetes and hypertension on pregnancy, birth, and later health outcomes; and the impact of prenatal nutrition, maternal stress, and other external factors on pregnancy outcome.

Future Goals/Objectives

Goal 1: Support research to understand the fetal antecedents of and biomarkers for disparities in hypertension, stroke, diabetes, and coronary artery disease. Use findings as a basis for prenatal and early intervention programs targeting special populations.

- Support studies to identify how intrauterine growth retardation and deficient intrauterine environments influence the developing fetus, providing the basis for future chronic disease. Define "normal" fetal growth, and identify other biomarkers as they apply to minority and nonminority groups.

- Determine whether maternal/fetal responses to external stimuli vary between racial/ethnic groups. Examine physiological response to stress, identify biological and genetic factors that account for differences, and identify other factors (e.g., history of small babies) to serve as markers or potential points for intervention.

- Support a prospective, multiagency, longitudinal, cohort study to understand the many factors (biological, psychosocial, physical/environmental, behavioral) contributing to differential health outcomes over the lifespan. This will include up to 400,000 participants and capture events that predate conception. It will also examine critical chronic and episodic events, including environmental exposures, as well as survey and biologic data to relate external events to physiological changes. Comparisons will be made across racial and ethnic groups.

Part 2: Understanding Disparities in Growth and Development—Obesity and Nutrition

The Facts

- Good nutrition must start early and is essential for optimal growth and development, and for preventing conditions (such as obesity or heart disease) that can start early in life.

- Achieving good nutrition is complicated, given biological mechanisms/genetic predisposition, and social, cultural, emotional, economic, and geographic factors.
  - Risk factors for diet-related diseases vary based on gender, age, race, ethnicity, and income; obese children may be at even greater risk for developing obesity-related conditions (e.g., hypertension, Type 2 diabetes, heart disease, gall-bladder disease).
  - The disparity in obesity is greatest among low-income teens, where the percentage of obese teens is twice that for middle/upper-income teens. Young African American females (6 to 17 years old) are 50% to 60% more likely to be overweight than young White females.

- The increase in obesity rates is fueling an epidemic of Type 2 diabetes appearing in Hispanic and Native American teens.
- Despite strong recommendations on the importance of breastfeeding, only 43% of African American women choose to breastfeed their newborns, compared with 66% of Hispanic and 68% of White women. This may place African American infants at a disadvantage for a healthy start.

Current Research

- The NICHD supports research concerning the early biological, developmental, nutritional, and behavioral mechanisms underpinning growth, nutrition-related diseases and conditions, complemented by social, cultural, and behavioral studies. Some targeted studies include:
  - Identifying risk factors for obesity-related complications in African American women—researchers have already identified differences in fat distribution and metabolism.
  - Developing innovative means to prevent obesity among African American adolescent females living in rural areas.
  - Developing childhood metabolic markers of adult morbidity in African Americans.

Future Goals/Objectives

Goal 1: Better understand the interaction between the biology of nutrition and growth with social and cultural forces to help prevent the early onset of health disparities.

- Expand NICHD research addressing African American teenage women, to understand the genetic, physiologic, metabolic, and behavioral characteristics leading to their increased risk of obesity; provide training opportunities for minority researchers in these clinical studies.

- Support research to assess factors that influence the calcium intake of different ethnic/racial groups, targeting children and teens, with particular reference to social, cultural, and ethnic influences on food preference.

- Identify how social and cultural factors interact with food availability to influence the development of dietary habits in infancy through adolescence. Assess the impact of these habits on disparities in obesity and other chronic conditions, particularly in Hispanic and Native American teens; include research on biomarkers, dietary supplements, and complementary feeding practices.

Goal 2: Eliminate the disparity in the percentage of African American women who choose to breastfeed their infants.

- Support research to understand the social, cultural, and behavioral factors that influence the decisions of women of various racial/ethnic subpopulations to breastfeed their infants and to continue breastfeeding throughout the first year of life. Target barriers that may exist in different racial and ethnic communities; share data to design interventions/education programs.

(E) EARLY ANTECEDENTS OF CHILD WELL-BEING AND ADVERSE BEHAVIORS

The Facts

- Racial and ethnic disparities in the development and well-being of children are striking when examined in relation to poverty and family structure:
  - In 1996, African American and Hispanic children were four times more likely to live in poverty than White children.
  - In 1996, children living in female-headed households were five times more likely than those in intact families to live in poverty; most African American and Hispanic children live in female-headed households.
  - Low-income minority children face a disproportionate array of problems, including low birth weight, contagious diseases, and childhood injury and death. Thus, these children are at greater risk for developmental delays and social/emotional and behavioral problems.
- The well-being of our youth, especially in minority communities, is also being threatened by increasing rates of unintentional and intentional injuries or violence.
  - Unintentional injuries account for over 40% of deaths in children ages 1 to 4, and 80% of deaths in young adults 15 to 24 years of age.
  - Death rates are high among minority children and adolescents for certain causes, e.g., Native American teens have disproportionately higher death rates from motor vehicle crashes than other racial/ethnic groups. Many of these deaths are preventable.
- Violence in the United States is pervasive.
  - On average, nearly 3 million children are reported as suspected victims of child abuse or neglect, and nearly 1,000 die from such maltreatment. A disproportionate number are minority youth.
  - Up to 20% of women report violence during pregnancy; at least 3 million children witness domestic violence each year, while millions more witness violence in their communities. Minority and low-income women and children are at increased risk.
  - Homicide has reached epidemic proportions for African American youth. Homicide rates for teens (ages 10 to 14) are three to four times greater than for Whites; they are eight times greater for older African American adolescent males.
- Unstable family structure may have additional adverse consequences. Infant deaths due to abuse are 3.4 times greater in the African American and 3.5 times greater in the Native American population than among Whites. These rates are also higher for infants born to African American teenage mothers who are living in unstable family situations.

Current Research

- The NICHD supports collaborative multidisciplinary research to clarify how biological, social, and behavioral processes interact with socioeconomic status (SES) to produce these health disparities.

- Many data collection and longitudinal studies examine national child health trends to inform policymakers, develop research agendas, and develop interventions. Many oversample minority populations to make comparative analyses and study disparities.
  - Notable efforts include the National Longitudinal Study of Adolescent Health and the annual production of America's Children: Key National Indicators of Well-Being.

- Other targeted efforts include studies concerning:
  - Changes in child care, child support policies, welfare reform policies, and medical care availability as they affect differences in family and child health outcomes.
  - How family and individual acculturation affects health care outcomes in various immigrant populations, particularly those of Hispanic origin.
  - New methods and models to help predict differences in such outcomes as birth rates, birth weights, infant mortality, adult mortality, STDs, and even gunshot wounds.
  - The family and developmental origins of behaviors that place youth at risk for unintentional injury and violence.

- Next, researchers must further clarify and better understand:
  - How SES, family structure, and parenting combine with other factors to produce disparities in developmental outcomes, child neglect and abuse, and unintentional injuries.
  - The antecedents of and impact of violence on development, starting in infancy through early adulthood.
  - How these patterns change over time and vary across racial/ethnic groups.

Future Goals/Objectives

Goal 1: Understand how the relationships between poverty, single-parent families, and related factors affect childhood well-being for minority children. Encourage targeted interventions to strengthen family support systems and sense of connectedness.

- Extend the "Science and Ecology of Early Development" (SEED) program, which is examining the complex interactions of poverty with other factors that influence developmental outcomes and resilience in children and families. Link studies to the evaluation of government intervention programs. Use the initiative to create an ongoing dialogue between researchers, policymakers, and program officials.

- As a followup to the NICHD conference on Parenting and the Child's World, encourage researchers to focus on the roles of parents in promoting healthy development, particularly among children of different racial/ethnic backgrounds and sociocultural settings. Examine how parenting interacts with a variety of other factors to influence children's social, moral, emotional, and cognitive development in these different settings.

- Expand support of the Early Head Start Fathers studies and the Early Childhood Longitudinal Study—Birth Cohort, to determine the antecedents, consequences, and meaning of parental involvement, program intervention, and other social/community factors, for child outcomes including health, social, and cognitive.

- Collaborate with the CDC's Healthy Futures Program, targeting White, African American, and Hispanic youth to determine the developmental path of health risk behaviors and adverse health outcomes.

Goal 2: Identify antecedent and etiologic factors, and understand complex interactions between social, cultural, biological, and developmental processes, which contribute to intentional and unintentional injury, violence, and other adverse health outcomes for minority youth. Use data to design, implement, and evaluate programs that promote healthful and preventive behaviors.

- Support interagency efforts to encourage research on injury prevention and emergency services for children affected by injuries, disabilities, illness, or violence. Clarify factors that place minority youth at greater risk, and develop effective preventive interventions.

- Lead trans-NIH efforts to develop a research definition and taxonomy concerning child neglect, ensuring that the definition considers the impact of social and cultural norms.

- Support research to examine the social, parental, and other antecedents of child neglect and abuse, while also determining the consequences of this behavior. Also identify the factors protecting infants and young children from neglect and abuse, with a focus on racial and ethnic differences. Include basic research in these efforts and the design and evaluation of parenting interventions to reduce rates of infant deaths due to such abuse.

- Examine, through multidisciplinary studies, the developmental antecedents, causes, and health consequences of unintentional injuries in childhood and adolescence, addressing environmental, social, and cultural factors that lead to racial/ethnic disparities, especially among Native American and Hispanic populations.

- Collaborate with the NIH Child Abuse and Neglect Working Group in developing a formal program to supplement ongoing projects that address child developmental processes in high-risk settings and violent/abusive environments.

- As part of the NIH Youth Violence Consortium, develop a comprehensive, collaborative effort to understand the antecedents, etiology (e.g., social, neurobiologic, cognitive, and academic), and outcomes of violent behavior in youth, with the goal of identifying different pathways among various racial and ethnic groups.

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- Support a collaborative effort to understand the immediate and long-term impact of domestic violence during pregnancy, and children's exposure to domestic and community violence. Address differential risk factors and impact across racial and ethnic groups.

Goal 3: Train and encourage more minority researchers to address these health disparity issues that affect the long-term well-being of minority families.

- Create research/training opportunities at Historically Black Colleges and Universities (HBCUs), and universities with a cadre of Hispanic and Native American Indian researchers for minority researchers to examine: 1) ways to strengthen parenting and a sense of connectedness between minority children, parents, families, schools, and communities; 2) unintentional injury; and 3) violence prevention. Include special outreach workshops.

(F) SCHOOL READINESS, COGNITIVE AND BEHAVIORIAL DEVELOPMENT

The Facts

- Children's early cognitive/behavioral development is key to later success in life; however, 1998 data show that African American, Hispanic, and American Indian students in 4th, 8th, and 12th grades were nearly twice as likely to perform below basic levels in reading. Similar disparities exist in math and science.
- By 2030, Hispanic children will comprise one-fourth of the Nation's total student population; yet, data show that:
  - Young Hispanic children lag behind White children in early school-related skills.
  - Many Hispanic American students are below grade level, which contributes to their higher dropout rates: e.g., 28% of Hispanic 16- to 24-year-old students dropped out of school, more than double the rate for African Americans (14%) and three times that for non-Hispanic Whites (8%).
- Data show that children living in poverty (many of whom are minorities) have smaller vocabularies at early ages and their vocabulary growth rate is less than that for more advantaged children. These early differences translate into disparities in later vocabulary use and IQ test scores, measures often used to predict future success at school and work.
- Low literacy also appears to play a role in the disparities affecting those children raised in poverty, many of whom are minority children. Of Hispanic and African American students, one-half or more of 4th and 8th graders, and one-third of 12th graders, read at or below the basic level necessary to read to learn. A large percentage of these students' parents are not high school graduates, indicating that adult/family literacy may be a factor.

Current Research

- The NICHD supports basic, applied, and translational research addressing all facets of children's development from infancy into early adulthood.
  - This includes studies on the neurological/biological, cognitive, emotional, behavioral, social, cultural, and related factors contributing to language development and disorders, attention deficit disorders, mathematical cognition, problem-solving, reading disabilities, and other learning disabilities.

- Many studies address lower socioeconomic and minority populations:
  - The NICHD pioneered studies to develop and evaluate programs like Head Start. Current studies are examining a father's impact on development, and how program interventions can strengthen a father's involvement, across racial/ethnic communities.
  - The Institute supports a range of collaborative and data collection activities, such as the Early Childhood Longitudinal Study—Birth Cohort, which oversamples minority populations to help analyze health disparities in developmental outcomes associated with school readiness.
  - In other studies, researchers are trying to: 1) understand how sociocultural factors influence English reading and writing abilities for Spanish-speaking children; 2) develop cross-cultural norms to aid early diagnosis of abnormal developmental patterns; 3) clarify family factors that influence early school performance among Latino children; 4) learn how racial/ethnic discrimination impacts academic motivation, school performance, and problem behaviors; and 5) learn how school-based interventions can promote achievement for at-risk youth in economically depressed and rural areas.
  - Early data from the NICHD/District of Columbia Public Schools Early Interventions Reading Project show that the program has significantly improved the reading levels of extremely high-risk, primarily minority, children.

Future Goals/Objectives

Goal 1: Identify barriers to school readiness and academic success for minority and low-income children; examine the effect of barriers in language, cognitive, and behavioral development and the subsequent and cumulative effect on school readiness. Design appropriate developmental interventions to ensure optimal development and optimal school readiness for these children.

- Identify whether linguistic barriers exist for non-English-speaking ("language minority") children. Address cognitive, developmental, and social/cultural factors to design appropriate interventions to ensure school readiness for these children. This includes studies addressing adult and family literacy.

- Determine factors that contribute to disparities in mathematics acheivement and how best to address them. Address cognitive, developmental, and social/cultural factors on a child's ability to learn mathematical concepts and information.

- Identify the unique developmental and linguistic challenges facing children of migrant workers, an often overlooked subset of children living in poverty. Define which aspects of their unique living environment might be advantageous in educating them, and the specific aspects of their living environment and lifestyle that are most likely to lead to disparities in their physical, linguistic, cognitive, and social-emotional development.

- Identify the interactions among biobehavioral, social, environmental, and community stressors leading to minority disparities in academic achievement and dropout rates among minority adolescents. Develop effective multidisciplinary interventions for reducing these disparities during the critical developmental period of adolescence. (See also Section E. Early Antecedents of Child Well-Being and Adverse Behaviors.)

G RESTORING FUNCTION AND PREVENTING DISABILITY

Part 1: Physical Disabilities

The Facts

- Minorities suffer a disproportionate incidence of trauma and illnesses, such as stroke, that lead to permanent disabilities. These disabilities add a double social, economic, and health burden to many minority families already at a disadvantage (e.g., minority victims of spinal cord injury are 2.8 times less likely to resume employment after injury than their White counterparts).
- Patients from minority groups access and utilize outpatient rehabilitation services less frequently than White patients.
- Preliminary data indicate that there may be no differential response of minority patients to acute rehabilitation interventions; however, these findings need further review.

Current Research

- The NICHD's medical rehabilitation research program addresses many issues that could help reduce the excessive disability burden on minorities, such as research to: 1) improve functional mobility, 2) promote behavioral adaptation to functional losses, 3) develop improved assistive technologies, 4) develop more precise methods of measuring societal and functional limitations, and 5) train minority researchers.

- The NICHD supports many stroke and spinal cord injury studies with large percentages or oversamples of minority participants; other studies lend themselves to such oversampling, especially those dealing with pediatric trauma.

- More research is needed to examine the issue of differential response to rehabilitation strategies.

Future Goals/Objectives

Goal 1: Improve rehabilitation outcomes for racial and ethnic minorities, building on newly established research programs. Identify specific social, cultural, and community factors that may lead to differences in: 1) responses to disabilities and to rehabilitation interventions, 2) access and use of outpatient rehabilitation services with varying impacts on health outcomes, and 3) risks in developing secondary conditions associated with disabilities.

Goal 2: Acquire basic data and develop appropriate interventions to reduce the double burden of being a racial/ethnic minority individual or family with a permanent disability. Build on newly established programs to identify specific barriers that impede racial and ethnic minorities from returning to work, reintegrating themselves into the community, and returning to school and to other educational opportunities.

- Supplement newly established sites in the Regional Rehabilitation Network (which integrate basic science with clinical rehabilitation studies) to link with minority institutions to address targeted questions concerning minority populations.

- Supplement grants stemming from a new initiative to encourage researchers developing innovative rehabilitation interventions, with the goal of targeting the needs of racial/ethnic minority families.

- Supplement new clinical rehabilitation networks targeting pediatric trauma and traumatic brain injury, to understand how socioeconomic, cultural, and other external factors influence short- and long-term rehabilitation outcomes.

Part 2: Developmental Disabilities in Children

The Facts

- Having children with developmental disabilities puts a disproportionate burden on minority families. Early data from an NICHD-supported study suggest that the divorce rate for families of young children with disabilities may be twice as high among African American families as it is for similar White families.

- Data suggest that the stigma associated with having a child with a developmental disability varies across racial and ethnic groups. This ultimately influences access to health services and health outcomes.

Current Research

- The Institute leads research efforts serving the needs of children, adults, and families with developmental disabilities, defining the etiology, pathophysiology, and epidemiology of these conditions. The NICHD also funds significant intervention research to aid the early diagnosis and treatment of developmentally delayed children.

- Some targeted research includes studies:
  - Addressing Hispanic families of children with mental retardation, to understand their unique psychosocial problems and how they are influenced by social/cultural experiences, beliefs, goals, needs, resources, and strengths.
  - Comparing culturally diverse, primarily low-income, ethnic families whose children may be at risk for developmental delay or related maladaptive behaviors. Researchers are examining how family adaptation varies among cultural groups and influences "resiliency."
  - Examining the early home and school events of Hispanic children at risk for educational and developmental disabilities; the effects of acculturation on the home environment of Asian American children with developmental delay; and the unique factors that may account for different outcomes among developmentally disabled adults from both African American and White families.

Goal 1: Promote stability in racial/ethnic families with disabled children by designing and implementing research-based interventions based on the special needs of these families. Address the father's role in influencing health outcomes of disabled children and understanding various social/cultural factors that may increase the risk for adverse family outcomes.

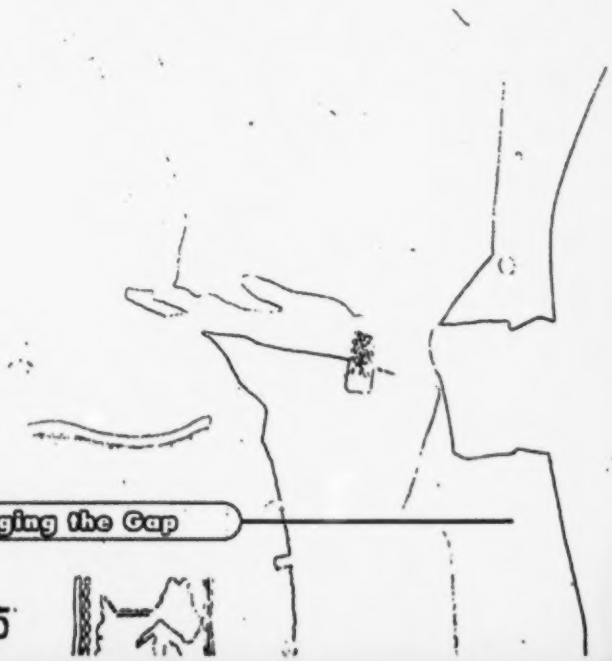
- Develop a multisite collaborative program to design and evaluate interventions to promote stability within families of disabled children. Assess data from ongoing studies and acquire range of racial/ethnic data as needed; design interventions with community advice/input; focus on those minority families where children with disabilities do well, to determine what particular factors or interactions of factors contribute to such successes.

(H) TRAINING AND CAREER DEVELOPMENT

The Facts

- Eliminating health disparities demands the same type of talent pool that exists to address our other science and engineering research needs. In particular, researchers are required who understand the needs of the community that this science is meant to serve.

- Providing the opportunity to network and meet with NIH and NICHD officials is also key to furthering the careers of minority researchers.



Current Training/ Career Development Programs

- The NICHD actively evaluates and makes recommendations on funding of Research Supplements for Underrepresented Minorities, and facilitates communication among minority investigators, at all levels, to help them advance their careers. The Institute also participates in the: 1) MARC Visiting Professors for Minority Institutions Program, 2) Minority High School Student Research Apprentice Program, and 3) Minority Biomedical Research Support Program.

- NICHD's small grants (R03) program offers opportunities to new investigators or those from institutions without well-developed research traditions or resources, to begin independent research. One goal is to encourage researchers from underrepresented institutions and institutions that do not traditionally apply to the NICHD, to initiate research programs or expand their research interests.

- The Institute works with minority institutions to increase applications from their students to the NICHD summer Intramural Research Training Award (IRTA) program and the Summer Internship program.

- To encourage networking and enhance our commitment to the minority researchers that we support, the Institute sponsors biennial meetings for these investigators. The meetings highlight the significance of the Minority Supplement Program, by recognizing their achievements as promising researchers, and by allowing them to meet personally with program and executive staff.

Future Goals/Objectives

Part 1: Training and Career Development Programs

Goal 1: Build on the strength of the NICHD's existing Institutional Training Programs (T32s) in the demographic behavioral, reproductive, maternal/child health, and rehabilitation sciences, which already target health disparity research issues. Expand these programs to better link to the minority communities that we serve.

- Target additional slots (in the short term) for existing T32s, institutional training programs, to pursue health disparities research, particularly targeting scientific areas outlined in this strategic plan, and encouraging the recruitment of minority researchers.

- Add a third level of NICHD review to substantively evaluate minority recruitment plans prior to making funding decisions for new or recompeting T32 grant applications. Re-rank the applications based on an additional score reflecting the strength of the applicant's minority recruitment plans.

- Encourage existing T32 programs to form consortia with Historically Black Colleges and Universities (HBCUs), Hispanic Serving Institutions (HSIs), tribal colleges, and schools in underserved areas to provide opportunities for students to train at the parent site.

Goal 2: Provide coordinated national clinical research opportunities for minority investigators and for persons seeking to conduct research on health disparity issues of importance to the NICHD.

- Build upon the NICHD's existing clinical research networks to create additional research training opportunities, in sites located throughout the country, for minorities and others wishing to pursue clinical health disparities research.

- Create a program to assist minority investigators in developing competitive research proposals (R01s) targeted to minority communities through long-term, intensive training in research methodology and grantsmanship, and the establishment of formal mentoring relationships between senior and new faculty.

Goal 3: Build on the strength of NICHD's existing career development programs in reproductive maternal/child health and the rehabilitation sciences to provide additional opportunities for minorities who are interested in pursuing health disparity research.

- Target new slots to existing K12, Mentored Research Scientist Development Program Awards, particularly encouraging minority researchers to pursue health disparities issues outlined in this strategic plan.

- Support "Scholar" positions in the Building Interdisciplinary Research Careers in Women's Health (BIRCWH) program, where investigators have been asked to address health disparity issues.

Part 2: Other Activities to Enhance Professional Development

Goal 1: Expand and strengthen incentives to aid and further encourage more racial and ethnic minority students to enter research careers.

- Encourage professional societies to help with outreach to local minority students in cities where conferences are held by supplementing conference grants, providing direct support or, if necessary, starting a new grant program.

① OUTREACH TO COMMUNITIES AND THEIR INSTITUTIONS

Part 1: Enhancing Participation of Minority Communities in the Design of Clinical Trials

The Facts

- The NIH Revitalization Act of 1993 mandated outreach to minority groups for recruitment into clinical trials. Much has been learned about enhancing minority recruitment, but more needs to be learned and applied.
- Clinical researchers need adequate numbers of women and minorities in clinical studies to enable them to detect and account for the significant differences in health status between racial and ethnic groups where they exist.
- Impediments to recruiting women and minorities into clinical trials include:
  - Reduced income, lower educational levels, reduced access to quality health care information and services, and impoverished living environments.
  - Lack of awareness of opportunities to participate in clinical trials, enrollment criteria, or enrollment mechanisms.
  - A shortage of minority biomedical scientists to recruit and effectively communicate with potential research participants.

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Current Outreach

- NICHD clinical trial networks customize recruitment and retention strategies to the needs of individual studies:
  - Phase III trials related to perinatal transmission and to gynecologic manifestations of HIV infection are located in minority community facilities, such as Harlem Hospital in New York and Howard University Hospital in Washington, D.C. Day care and transportation expenses are paid; some sites provide meals for the women and children when clinic visits require a full day.
  - Researchers conducting intervention studies for high-risk pregnant women and their infants reduce the number of trips required by study subjects by scheduling clinical trial visits with other medical care appointments at the same treatment facility. Connections to social services provide "one-stop shopping" and incentives to keep appointments.
  - In rural areas, investigators travel to outlying clinics and community centers, some even make home visits to hard-to-reach populations.

Future Goals/Objectives

Goal 1: Ensure the enrollment of a greater number of individuals from various racial and ethnic minority communities in clinical trials. Ensure that the Institute's intramural and extramural investigators understand community characteristics and needs, receive adequate training and guidance, and communicate information about the trials to appropriate health care providers and to the community.

- Support research using focus groups and increased interactions with health care and patient representatives from the communities in which new clinical trials are planned to: 1) apprise the community of the nature and scope of the research, 2) build the community's trust in the research effort, and 3) ensure that the trial design adequately meets community needs and concerns. Apply appropriate social marketing and outreach techniques to enhance recruitment where necessary.

- Enhance training opportunities for intramural and extramural investigators in designing and conducting trials, and in outreach techniques, to better meet the needs and concerns of racial and ethnic populations.

- Establish a committee to develop guidance for NICHD intramural and extramural staff in the design, implementation, and evaluation of clinical trials that seek to recruit minority subjects. Use guidance to enhance extramural staff interaction with investigators initiating trials in these populations, working to supplement their current population base, or falling short of expected recruitment/retention levels. Intramural investigators will be given guidance and suggestions when conducting their clinical trials.

- Continue to expand the cadre of minority researchers in scientific areas addressing our mission to increase the availability of clinical researchers who are able to communicate with research subjects in a manner they can understand and trust. (See also, the training and career development objectives above.)

Part 2: Outreach to Minority Communities, Youth, and Their Institutions

The Facts

- Getting children engaged in the world around them and their own health is a first step in feeding the pipeline for biomedical research scientists of the future. It is also the first step in sparking the interest of children, their families, and their communities to take active steps to safeguard or improve their own health.

- It is important to encourage scientists to periodically take stock of their research accomplishments, and to consciously translate their research findings not only to fuel the next scientific discovery, but to improve public health.

- We need to listen to various communities and learn about their information needs and health concerns, and reflect these needs when we develop our research priorities.

Current Outreach

- In 1991, the NICHD "adopted" Highland Elementary School, where 89% of the students come from minority populations (primarily Hispanic, African American, and Asian American), and where 60% of the children qualify for free or reduced price lunches. The NICHD activities include:
  - The Scientist Volunteer Program, where individual scientists visit classrooms, help teachers to design projects, and work with children to promote their appreciation for health-related topics and the scientific method.
  - "Presentation Day," where intramural and extramural scientists and staff members visit and speak on health topics.
  - A pen pal program, providing support for many children throughout the school year.
  - Tutoring for individual children with special needs.
  - Participation in programs to help the school acquire needed computers and technologies.

Future Goals/Objectives

Goal 1: Work with children and the educational systems, particularly those serving racial/ethnic communities, to enhance their interest in and excitement about science and health.

- Enhance NICHD's pioneering efforts to partner with local schools and educators, and to work with children from disadvantaged and minority backgrounds.

- Enhance the NICHD Web site by adding a "children's corner" targeted to the interests of young children, their parents, and teachers. The site will be designed to be attractive for children, reflecting their interests and providing health information which is both culturally and age appropriate.

Goal 2: Actively identify and translate NICHD research findings important to various minority communities to help them and their health care providers obtain and use research-based information. Actively seek the advice of communities in preparing these materials.

- Support the analysis and synthesis of research findings most relevant to minority communities, developing materials useful to providers and members of racial/ethnic communities. Areas in which new

targeted materials will be developed in the short term include: 1) nutrition for pregnant mothers and for children and teens, 2) reading and related school readiness issues, and 3) parenting. Also, expand efforts to publicize the NICHD Clearinghouse in minority communities.

- Through targeted research studies, focus groups, and working with community leaders and organizations, determine future information needs and gaps among various racial, ethnic, and disadvantaged communities, particularly in areas addressed in this plan.

Goal 3: Increase awareness of the scientific community and policymakers to the issues outlined in this plan, and help translate interest into viable NICHD research efforts.

- Support the development of targeted issue papers, articles, speaker series, and forums to translate the newest NICHD scientific findings and projects addressing health disparities into implications for health care researchers, health care providers, policymakers, and community/advocacy groups. For example, sponsor regular symposia and develop summer scientific/policy internships, linking whenever possible to HBCUs, HSIs, and similar institutions.
- Identify a coalition of members of the minority community, as well as health care providers, foundations, and others that serve the minority community to: 1) advise and assist the NICHD in developing goals for health disparities research through a planning process, 2) assess the Institute's success in meeting goals/objectives, and 3) generally provide a sounding board for minority community issues related to health needs, research, and outreach.

Goal 4: Ensure that the NICHD, and the researchers we support, actively contribute to the communities standing to benefit from our research.

- Determine the feasibility of developing and implementing a standard policy that requires both intramural and extramural recipients of NICHD research funds to assess and translate their research findings into media that will help educate the local communities in which they reside or serve. Materials should be proactively and regularly shared with local communities.
- Lead and expand support for activities that allow the NICHD to participate in local community health activities and functions, particularly those serving minority and economically disadvantaged populations, around the country.

Appendix—Roster of Advisors

Although this planning document has benefited from the input of the public and of many scientists within and outside the NICHD, we wish to particularly note the advice of the following panel of advisors convened by the Institute Director.

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For additional information about other NICHD strategic plans and research, please visit our Web site at:
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Health Disparities: Bridging the Gap

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